Realist evaluation of the impact of paediatric nurse practitioner clinics, specialist paediatric nurses, and a children's community nursing team in deflecting attendance at emergency departments and urgent care centres by children with long-term conditions

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1 CONTEXT OF THE WORK

There is a large body of evidence of the growing pressure Worldwide on emergency departments (Amiel et al 2014, Cooper et al 2019). The outcome is long waiting times and overcrowding of departments (Khangura et al 2012). A major cause of overcrowding is the number of non-urgent cases presenting in the departments (Burns 2017, McCusker et al 2014, Morley et al 2018). Many of these cases ought to be considered by non-urgent primary care services (Cowling et al 2013, Knowles et al 2017, Mason et al 2017, Royal College of Emergency Medicine 2015, Uscher-Pines et al 2013).

It has been the case for some time that a majority of patients attending emergency departments are classified as non-urgent cases, and many are discharged without treatment. This is the case in Canada (Brown et al 2001), the US (Kubicek et al 2012, Phelps et al 2000) and the UK (Coleman et al 2001, Brown et al 2001, Hendry et al 2005, Royal College of Emergency Medicine 2015). Estimates vary, but the proportion of cases that could have been treated just as well in a primary care setting is high: perhaps between 35% and 65%. The picture is no different in relation to paediatric patients attending emergency or urgent care departments. Approximately 25% of children in the UK will be presented at an emergency or urgent care facility, mostly with minor injury or illness (Hendry et al 2005, Mason et al 2017, McHale et al 2013). Again, the picture is similar in other countries: for example, France (Costet Wong et al 2015) and the US (Zimmer et al 2005). Increasingly, it is recognised internationally in Australia (Lowthian et al 2011), the US (Burns 2017), and the UK (Royal College of Emergency Medicine 2015, Care Quality Commission 2019) that this results in patients who are in need of urgent care experiencing undue delays. Moreover, this carries risks to staff wellbeing through adverse workload, occupational stress, violence, demotivation and dissatisfaction (Royal College of Emergency Medicine 2015). That the current levels of demand and stress upon urgent care departments is not sustainable was recognised in a briefing paper to NHS England by the National Medical Director (Keogh 2017).

A national strategy of diversion or deflection of patients from urgent care facilities has been in operation in England for some years, though with only moderate effect, and the problem continues to increase. Primary care practitioners, GPs, nurses, heath visitors, pharmacists and many others have accepted their share (and more) of this additional work to address non-urgent needs, but one outcome of this has been overwhelming demand on the services. Despite best efforts, including extending working hours with evening and weekend appointments, the availability of GP appointments cannot keep up with increased demand. Initiatives to refer some of this workload to community nursing teams have shown that this can be successful, but only if the service is readily visible, GPs can be confident of the quality of the varied elements of the nursing service, that they are aware of the service and what can be offered, and communication between the two primary care elements is effective (Kyle et al 2013, Fisher & Flint 2014). Similar active, positive links with health visitors and school nurses are crucial to the effort particularly in health promotion and the building of self-agency and self-help skills in parents and older children.

In 2016 localities across Greater Manchester were asked to develop transformation plans which would include several quality improvement initiatives. These were developed on an invest to save model. Heywood, Middleton and Rochdale CCG and Rochdale Local Authority, as an integrated children's service, proposed to test new ways of working which sat outside traditional 'business as usual' or current commissioning agreements. These initiatives cross health and social care boundaries and included the following.

1. The development of a Family Services Model, with clear thresholds of support for children and their families across various levels of need. This model includes a locality or neighbourhood approach to early identification of need, early help, a multi-disciplinary approach and wrap-around specialist intervention when required. Additional investment supported the implementation of new locality teams and strategic development with a view to increasing the initiation of Early Help Assessment and Early Coordinated Intervention. The aim was to improve outcomes for families, reducing the number of families escalating to child protection status and the number of children entering the care system.

2. The Paediatric Nurse Practitioner (PNP) model was developed to support children who were acutely unwell but did not require urgent or emergency care. The service would be accessible by self-referral for children who were unable to gain access to an appointment with the GP due to capacity. Children would be seen on the day and receive a thorough intervention, assessment and education package which would support their acute need in a community or locality setting. The aim of the service was to 'deflect', or decrease, unnecessary attendance at accident and emergency departments and in-patient admission. The development of new ways of working in children's acute health services is complementary to the above locality model.

In 2018, the Greater Manchester Children's Health and Wellbeing Board developed a 10-point strategy to achieve its objectives, the sixth of which was to reduce unnecessary hospital attendances and admissions for children with long term conditions such as asthma, diabetes and epilepsy. Funding was secured from Manchester Academic Health Science Centre to commission an exploration of the impact of the Paediatric Nurse Practitioner Clinic within the context of the Family Services Model and the impact that the service was having on reducing attendance at urgent care centres or admission to hospital.

The PNP Clinic is commissioned through transformation funding but sits within the Children's Acute and Ongoing Needs Service (CAONS) which is commissioned by the CCG. Until 2019 this service was provided by Pennine Care NHS Trust and is now provided by the Northern Care Alliance NHS Group. This context is important to the study in that the CAON service operates as an integrated model which includes paediatric nurse practitioners; children's community nursing; specialist nurses for epilepsy, diabetes and respiratory conditions; consultant paediatricians; occupational therapy; speech and language; orthoptics; and latterly health visiting and school nursing services. The service is accessible by a single phoneline triage system, and data is captured using a single information system.

2 STRUCTURE OF THE EVALUATION

A realist evaluation approach (Pawson & Manzano-Santaella 2012) was adopted since this goes beyond identifying outcomes to addressing the mechanisms by which outcomes are achieved and change is realised (for example, adoption of ways of working or the establishing of new pathways) as well as the influence of context in producing those outcomes (including the response of practitioners and patients to the programme). In MRC terms, this equates to establishing *"which are the active ingredients of the intervention?"* (Medical Research Council 2009). This process of establishing context, mechanisms and outcomes was applied to each facet of the work to answer the evaluation questions.

1. To what extent does the paediatric nurse practitioner service deflect attendance at A&E and admission to hospital?

2. What factors do parents hold to be essential to their decision to use the community-based service rather than to attend an urgent care centre or A&E department (on one occasion or in future)?

3. What contextual factors are at play in influencing this decision?

4. What opportunities are there for wider learning for the partnership, GM, and beyond?

Data Collection Activities

A) This began with service users' perspectives. A total of 1111 responses from 15 months of Friends and Family Test responses (See Appendix 1) were reviewed manually. The degree of overall satisfaction with the service was established (identified by responses of "Extremely likely" or "Likely" to recommend the service, and "Extremely happy" or "Happy" with the service provided). The issues that parents had found important to raise in the free-text questions were examined, grouping these into three major areas, each with three sub-categories of features (Appendix 2).

B) Non-participant observation of paediatric (advanced) nurse practitioner (PNP) consultations was undertaken on four separate days in clinics held at the Whitehall Street clinic by agreement with the families.

C) Each consultation was followed by an interview with the family in a separate consultation room. All attending families agreed to this readily. A forced-choice questionnaire that was based on the categorised responses to the Friends and Family Test was used to start the discussion. This technique is useful when respondents report complete satisfaction with everything, forcing a ranking of a list of items which are all important. The thought required to complete the ranking can help to make underlying reasons for the importance of items more explicit. There followed a free-ranging discussion of the reason for attending the clinic, alternative options, what was important about the exchange, and whether future behaviour in choice of service to approach might be influenced.

D) One-to-one interviews were held with specialist nurses for long term conditions to investigate their role and efforts to prevent attendance at urgent care facilities or admission to hospital.

E) Telephone interviews were conducted with parents of children who accessed the specialist nurse service. Parents were invited to offer their phone number for interview to the researcher. All ten parents who received the invitation from the specialist nurse agreed to be interviewed. One parent's circumstances meant that communication by text message was the preferred mode. In all cases, the researcher's questions were made available in advance, allowing parents the chance to think about their response.

F) Review was carried out of the Children's Community Nursing Team (CCNT), its activity, and referral pathways through discussion with the team leader and review of reports and other documentation.

G) Supplementary materials provided by the CAON service both in hard copy and as electronic media were reviewed.

H) Two final group discussions were undertaken with CAON nurses from across the service to ensure accuracy of the report and to clarify any remaining uncertainties.

Ethical Issues

Formal research ethics approval was secured from the University of Salford Research Ethics Committee for the School of Health & Society. (See Appendix 3)

All participants agreed verbally to take part. While all were offered a participant information sheet and consent form, almost all preferred an oral explanation (though taking the PIS) and giving verbal consent. The risks to participants were negligible, and they remained in control of how much time they chose to contribute to the project. A number of children and young people made their own thoughts explicit in addition to what their parents had to say, though most were in the clinic because of feeling unwell and preferred their parents to interact with the researcher. One telephone interview with a parent was clearly being monitored by a teenage patient who made her points through her mother.

No unexpected ethical issues arose.

3 PAEDIATRIC NURSE PRACTITIONER CLINICS

The researcher attended the Whitehall Street PNP clinic in Rochdale on four occasions to observe consultations and to interview families. Sometimes, when there were no additional patients waiting to be reviewed, the nurses worked together, and at other times they undertook the consultations individually. Every family that attended agreed to speak to the researcher. Usually, this was in a separate consultation room, though when there were no other patients present and, for example, a family was waiting for urine collection to be completed then the interview was conducted in the clinic waiting area.

Learning from the Friends and Family Test responses

The responses to the local Friends and Family test questionnaire over 15 months were reviewed. A total of 1111 individual responses were available from the whole questionnaire (including the core national question), with 1020 responses about alternative services that might have been accessed.

How likely are you to recommend our service to friends and family if they needed similar care or treatment?

With the exception a single case ("neither likely nor unlikely"), every response (n=1110) was either "likely" or "extremely likely". Effectively, this represented 100% satisfaction, and it was reflected in the response to the third question: *"How happy were you with the service provided today?"*

The fourth question asked, *"If this service was not available, where would you have taken your child?"* The possible responses to this item had changed a little over the 15 months but including all options of (a) urgent care centre (Rochdale Infirmary) and (b) A&E department at Bury, Oldham or North Manchester as a single item allowed for comparison over time while maintaining the focus of the evaluation.

Over the 15 months, the alternative sources of consultation were BARDOC (out of hours GP service) 34.3%, urgent care centre or A&E department 41.9%, manage child at home 7%, and other (almost all - try for next day GP appointment) 16.8%.

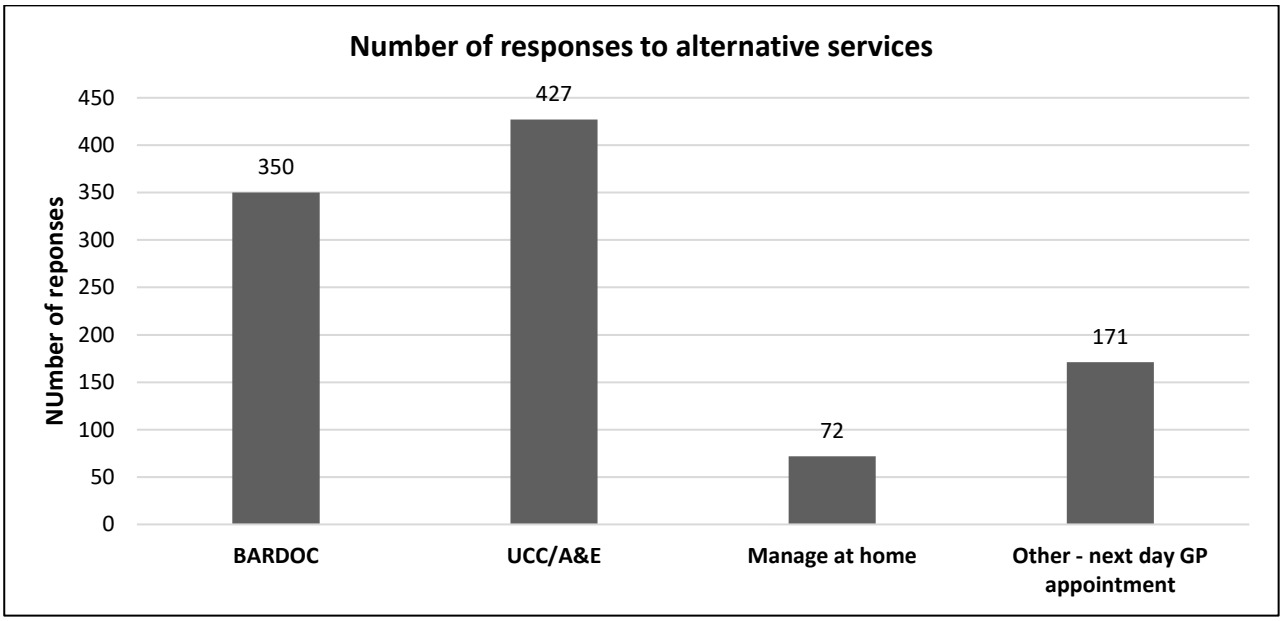

Figure 1: Choice of alternative service if PNP clinic were not available

Slightly more parents indicated that without having the opportunity to receive the PNP services they would have attended the urgent care centre in Rochdale rather than one of the three A&E units, but most were from the Rochdale area, and the Rochdale Infirmary urgent care centre was only across the road from the clinic. There were two main changes over time, other than an overall increase in the number of patients and therefore of responses. In the first five months of the period, parents reported being less likely to manage the child at home and more likely to try for a next-day GP appointment than those in the last five months. There was a persisting expectation of needing to attend the urgent care centre or an A&E department in the absence of the nurse-led clinic.

Question 2 sought explanation of the main reason for the response to question 1, while Question 5 invited further comment about the service provided on that occasion. Since there was close similarity in responses to these two items, they were considered together and used to form the basis for the interviews with families.

Learning from observation of consultations and interviews with families

Ranking the most important aspects of the service

Given the overwhelmingly positive evaluation by parents of the service, a brief ranking questionnaire was designed to force an indication of what were the most important factors contributing to their satisfaction (See Appendix 2). This allowed parents to maintain their position that "everything is excellent" but promoted thought about why different factors mattered and drew out issues for further discussion. Three main aspects of the service were

represented (according to reporting guidelines for the NHS trust): access to the service, clinical care, and staff attitude. Under each of these headings, parents were asked to rate three specific facets from 1 (least important) to 3 (most important). These items were taken from review of the free text comments made in response to questions 2 and 5 of the Friends and Family feedback questionnaire. Since all items were considered to be important and had been reported as such without prompting by parents in the Friends and Family feedback forms, the absolute ranking of these is to be considered with circumspection, and, furthermore, most parents experienced great difficulty in making a selection. Following the ranking exercise, the conversation continued to explore the reasons for the decisions that had been made and why various facets of the service were important at all.

Table 1: Forced ranking of the importance of facets of the PNP service

ITEMS	**Rank**
ACCESS TO THE SERVICE	
Ease of access	2 – Fairly important
Availability of same day access	**3 – MOST important**
Length of wait and being seen on time	1 – Least important
CLINICAL CARE	
Attention / interaction with the child	2 – Fairly important
Knowledgeable, explanation, information	**3 – MOST important**
Reassure, support, understand	1 – Least important
STAFF ATTITUDE	
Being good with the children	2 – Fairly important
Being friendly	1 – Least important
Being polite and professional	**3 – MOST important**

Parents' explanations of their satisfaction and ranking of items.

An important part of parental satisfaction and diversion from attending a hospital with their child was the way in which the PNPs addressed the whole problem in context, going beyond the presenting condition and ensuring that parents had told everything that wanted to tell. It was not only the engagement with the parent that mattered. The way in which the nurses spoke to the children and made the effort to explain to them and to counter any anxiety was also noted.

Following five admissions to hospital, the child was referred by the GP for asthma nurse intervention. The parents preferred the nurse service because a GP appointment was so difficult to get (especially one on the same day), and there was not enough time in the appointment. The GP service was not suitable for seeing the problem in context or to explore concerns thoroughly, sometimes when it is difficult for parents to find the right words or to express the problem accurately and fully. This nurse was very knowledgeable, took time to listen and to take everything into account, and was friendly with the patient and the other four children who, of necessity, had to attend, too. The parents would always come back to this service rather than going to urgent care or the GP. At urgent care, they felt that they were perceived as being inappropriate attenders (and there was also pressure of time and waiting patients), while the GP was not as knowledgeable and had too little time to pay attention properly. They were particularly keen to discuss matters with someone who was friendly and understanding.

Figure 2: Case study of a preschool child with chronic asthma

The infant was suspected to have a urinary tract infection due to a strong odour from the urine. The mother and grandmother had recognised the need for professional assessment and treatment, but the mother was told in a telephone call that no appointments were available for another two days. They would have gone to the UCC but found the number for the PNP clinic. They were especially impressed by the professional approach and thorough assessment undertaken by the nurse. This had two effects. First, they expressed more confidence in the accuracy of the assessment and diagnosis and in the prescribed treatment than they would have experienced with the GP (largely because of the care taken to make a complete examination). They also felt better informed such as to be able to make alternative decisions in future instances of similar illness. They thought that this was partly because of what the nurse did and explained, but also because there was no feeling of being rushed and needing to let the professional move on to the next case. They acknowledged that GPs simply did not have time to offer a similar response. They would prefer to return directly to PNP in future and expressed the need for a 24 hour, 7 days per week PNP service.

Figure 3: Case study of a 10 months old girl with probable urinary tract infection

Even when the only intervention had been reassurance and advice, the parents were content with the outcome. The notion of "inappropriate attendance" has been addressed previously and further research is currently underway to explore and understand parents' reasons for presenting a child at emergency services with minor illness and their expectations of what might happen during the consultation. However, some parents had perceived a negative response to their concerns previously but felt valued and respected in the PNP clinic visit. This, in turn, left them with greater confidence to take the child home and manage the condition there according to the advice provided. The nurse's knowledge, interpersonal skill, and willingness to spend time listening were all emphasised as part of this newly-found self-agency.

Although most parents recounted failed efforts to secure a GP appointment (including the BARDOC out of hours GP service), most seemed to realise that this was out of the control of the GP. When an appointment was secured, parents were acutely aware that the GP was also under time pressure and unable to devote as much time to each consultation as they would like. They understood that this limited how thorough a GP could be, and that they would, of necessity, focus on the immediate complaint without the ability to listen to further details. Certainly, there would be insufficient time for the provision of detailed information. They knew that GPs had a strictly limited time for an appointment and that efforts had been made to make services available at additional times, yet they were consistently frustrated at not being able to pursue this route of support.

In contrast, the longer appointment with the nurse was much valued since this allowed time for parents to explain their story properly, to receive a full explanation, and for additional factors to be taken into account. The level of examination and questioning was held to be enhanced in the nurse-led clinic. Early access to assessment was perhaps the most important factor of all in choosing which service to approach. Parents preferred a set appointment time, even if considerably later in the day, and were happier to wait at home with the child (rather than in an A&E waiting room). Given that appointments in the clinic ran to time during the observed periods, this system seemed to work well.

Once they knew about the nurse-led clinic, some parents admitted that they no longer really bothered to try for a GP appointment, contacting the PNP clinic directly instead. While not ideal in a logistical sense, this demonstrates the commitment to using this service preferentially. Parents did not feel that they had been "deflected" from urgent care – rather that they had chosen to access a better option.

Having waited 20 minutes on the phone and still been 14th in the queue to be put through to reception at the GP surgery, the mother called PNP and was given an immediate appointment. She had been to A&E previously with the child with a five hour wait and would have had to do that again without this service. Early access was of the greatest importance, though she had not expected such rapid access. The time taken to explain to the child what was being done and why, and also to the mother about the diagnosis, the likely course of the disease, and much more useful information and advice for further management was particularly valued. She knew that this would not have been possible at the GP surgery, especially given the obvious pressure on availability of appointments and therefore on consultation time.

Figure 4: Case study of a seven years old girl with tonsillitis

There were many reports of feeling empowered through the information provided by the nurses, by their own skills being enhanced through explanation and demonstration, and their own self-agency being revealed. The service provides information in several mediums: orally, printed information sheets and leaflets, a Facebook account, and apps. Different parents valued differing modes, but most remarked on the helpfulness of information to promote their own ability to cope at home and to avoid the need to seek help in future.

The mother had tried to get a GP appointment, but none was available. She explained that she would have gone to the UCC but had contact details for the PNP clinic already, so she called. Same day access was the most important issue for her. She had thought that she would have had to try the GP again at 6pm but felt that it was unlikely that there would be an appointment then, either, and she would have ended up at the UCC with the child more ill than when presented to the PNP service. The time spent in the appointment was appreciated, particularly including advice and signposting to an app for future reference. She had learned more than she could have done from the internet and was satisfied that she had accurate information specific to her daughter's age and condition. She felt convinced by the nurse's ability to make the right decision and to prescribe the right medicine (an Ipratropium inhaler with spacer had been provided): more so than during a rushed GP appointment.

Figure 5: Case study of a 6 months old baby with a wheeze

Searching the internet for relevant information was thought to be a haphazard means of self-information, particularly given the lack of quality control, but the choice of mediums through which to access professionally designed or vetted materials was clearly a different matter. Differing aspects of the material may have been more suited to some than to others, but the videos of common childhood illness were remarked upon particularly.

The professional approach taken by the nurses was noted time and again. This also included the demonstration of confidence and skill in interaction with the children, many of whom were upset and irritable. The methodical working through with examination, questioning, listening, and testing was acknowledged, resulting in a feeling of confidence in the conclusions derived by the nurse and in the treatment or advice that was provided. This, in turn, lent confidence to the parent's acceptance of the safety of taking the child home. This was often reinforced by allowing a family to wait for an hour in the peace of the waiting room to see if a pyrexia subsided after treatment, to go home and bring the child back later once a urine sample had been secured, or to go home and receive a telephone check later to ensure that the problem has resolved or was at least confidently under control. Such flexibility was welcomed by parents. The father of a seven-year-old boy with large tonsils, for example, was pleased to receive a clear explanation of what was happening, and also to take home a prescription for antibiotics to be dispensed later should the condition not start to resolve. He was content that there was no danger to his son and that he was in control of

the situation, with an action plan and clear instructions regarding when to take further action if needed (and how to recognise the need).

> After trying to secure an appointment with the GP and BARDOC without success this toddler's mother had found the contact details for the PNP clinic and had secured an appointment on the same day. She had been particularly impressed with the thoroughness of the assessment and the compassion that was shown by the nurses in dealing with the child who was upset and crying. She had no hesitation in accepting the decision-making of the nurses (two had attended to the child) and was reassured by their explanations. The additional information - both printed and oral - were useful, and the mother felt that she would be able to manage other episodes of this or other minor illnesses more confidently without needing an appointment. However, when asked, she expressed a clear preference to use the same service again should professional help be needed.

Figure 6: Case study of a 17 months old toddler with a rash and viral illness

Summary

Parents expressed satisfaction with the service for a number of reasons, and these correlated well with the rationale that they gave for feeling no further need to attend an urgent care facility. They had all expected to have to attend either an urgent care centre or an A&E department in the absence of the PNP service. Most had been unable to access a primary care appointment (GP or BARDOC), and PNP was the only remaining alternative to a secondary care centre.

Their satisfaction was based on the availability of same-day access (regardless of the time), the level of confidence in the judgement of the practitioner and the treatment provided, the thoroughness of the assessment, and the information that made them understand the condition and able to cope better at home.

The calm atmosphere and the polite, friendly approach with no feelings of being blamed or criticised were essential contextual factors.

4 SPECIALIST NURSES FOR CHILDREN WITH LONG-TERM CONDITIONS

Once it became clear that most children being taken to the PNP clinics did not have long-term conditions other than asthma, the project was expanded to review the contribution to deflecting attendance at emergency and urgent care units made by paediatric nurse practitioners in specialist practice: diabetes and epilepsy.

Learning from interviews with specialist nurses

Paediatric Diabetes Specialist Nurse

There is currently only one diabetes specialist nurse in CAON for NHSHMR. She has a caseload of 110 children, mostly with T1DM. There is an agreement that diabetes nurses will share cover across the North East Sector (Rochdale, Oldham and Bury) to cover sickness and absence and a dedicated leadership role within Pennine Acute to support this function. There is no local out of hours service and families are advised to contact CCNT or the registrar on call at times of emergency when the specialist nurse is not available. Families are encountered in clinics, at home and on the ward. Key elements of the service and maintaining children in the community without admission to hospital are support from the point of diagnosis, the presence of a (new) paediatric diabetes lead on the ward at the Royal Oldham Hospital, and close contact before discharge from hospital for advanced reassurance.

Diverting children from A&E is needed mostly when parents are concerned about episodes of diarrhoea and vomiting with subsequent disruption of diabetic control. Parents will call directly to the specialist nurse's dedicated mobile number. The response might be to provide advice, to offer support with confidence, and to call back in an hour to ensure that the

situation is improving. Remote review is available more recently, with families able to present data to clinicians for immediate treatment review.

When children have attended A&E they are debriefed by the specialist nurse, discussing the parents' concerns, what they might have done differently, perhaps confirming that admission was needed, and reprising previous advice and information. Parents can gain immediate access to the ward when needed, and this increases their confidence to try to continue managing problems at home (with support from the specialist nurse).

Although there is no automated digital access to this data, the nurse compiled the following from patients over the previous 12 months.

- 14 individual patients had been supported with telephone advice and close monitoring during an episode of illness that could otherwise have resulted in admission to hospital.
- 7 of these 14 had 2 or 3 repeated episodes of separate illnesses.
- 2 required a GP consultation for additional treatment for infections.
- 2 attended the hospital.

- There were a further 26 additional contacts for sickness support.

Paediatric Epilepsy Specialist Nurse
Currently, the epilepsy service is quite disjointed across GM. There is one specialist to cover the NHSHMR footprint. Efforts were being made to streamline the services. Compared to the corresponding diabetes service, some opportunities to enhance the effectiveness of the service are being missed. For example, there is no period of time in hospital at the beginning to implement a teaching programme and to establish elements of self-care though this has been seen to be central in-patient management in other specialities. The nurse's caseload (of known families) is more than 200, and this can be even higher at times. However, not all cases are active, and families require differing levels of intervention depending on severity or complexity of need. The nurse engages in direct contact through clinics, schools, home visits and other means.

Children are kept out of hospital by three main means (the last one not currently available).

1) There is direct contact with the nurse specialist for health promotion, planning ahead (e.g.; what will happen when the child change schools or what to prepare for a holiday in the US), diagnosis of the likely reason for changes in status or stability of the condition, or immediate change to the individual treatment plan. Repeat (follow-up) visits are an essential part of ensuring an effective service.
2) Effort is put into preparation of families to be self-managing and able to avert panic with consequent A&E attendance. Key aspects of this are minimising the frequency and severity of seizures, maximising the family's self-care ability, and engaging in proactive risk-management with the child and parents.
3) Although not currently available, a third factor would exert significant impact. A "knowledgeable presence" on the ward could effect immediate teaching (for the family's skills set) and psychological intervention (to address anxiety, resilience, and confidence) from the point of diagnosis. The nurse could also effect on-site short-term intervention to prevent unnecessary admission when families have arrived anyway (including in A&E or urgent care units).

There are two main reasons for attendance at A&E or admission to hospital: parental anxiety and prolonged seizure (of more than 5 minutes). Perhaps a third of the caseload will attend an A&E or UCC at some point (with seasonal variation). More than half of these are probably not necessary. Cultural factors, mismanagement by the family, misunderstanding of an aspect of care, or simply wanting to see the same doctor again are common reasons for this, though lack of a weekend service is a recurrent issue. The myth of "open access" persists, so families present at the ward and are redirected to the A&E department. The "knowledgeable presence" on the ward with access by A&E staff would reverse much of this, as would a weekend service.

Asthma

The arrangement for support for children with asthma is rather different. The responsibility for the long-term, routine clinical management of children with asthma rests with GPs. However, a number of criteria prompt review of any child aged 0-19 years with recurrent asthma and wheeze by the Children's Respiratory Nurse Specialist.

- Two or more referrals to the urgent care centre in the last 6 months or
- More than four GP consultations within the past 3 months or
- More than two A/E attendances within the past 6 months or
- Two or more hospital admissions in the last 3 months.

Similar referral will be made following the prescription of a course of oral steroid by the GP, or particularly difficult cases of inadequate response to treatment, triggering an extended (30 minutes) appointment. This means that sometimes the Children's Respiratory Nurse works to avoid further admission to hospital, though the normal mode is avoidance of initial admission. That said, some children with asthma are supported via generic children's community nursing pathways, although there is currently no specific requirement to capture this data. All health professionals in primary, secondary and tertiary care can refer children to the service, as can other professionals working with families such as social workers

The issue of children under six years with suspected asthma is a particular problem. Such children will often present with viral wheeze or other common respiratory signs and require treatment anyway while diagnostic testing proceeds. The absence of the confirmed diagnosis can cause some professional confusion in how to manage the clinical presentation. Considerable time and effort are put into supporting primary care staff with updates and training, as well as with materials to use with families.

Learning from interviews with parents of children accessing these services

Ten families were invited to be contacted by the researcher for a telephone interview to discuss their experiences of the specialist nurse service. Three questions were sent to the parents in advance.

1) Has your child needed to attend the A&E department or be admitted to hospital in the last 12 months or so? (If so – what was the reason?)

2) What does the specialist nursing service do that helps you to manage your child's condition at home instead of needing to go to the hospital when things start to go wrong?

3) What is most important in these factors, and what else would make it easier to stay away from the hospital?

The patients who had attended A&E or been admitted to hospital had done so according to their protocol (for example, if a convulsion lasted longer than 5 minutes) or because of an unconnected medical problem such as appendicitis. A number of the children had more than one co-morbidity or a disability. None of these would be considered an “inappropriate” attendance.

The instilling of confidence in parents was a major factor. Parents felt confident in the advice and instruction provided by the specialist nurse, and in turn this enhanced their own self-confidence to be able to deal with problems. Reassurance and feedback emphasised the messages of parental competence and ability, together with regular follow-up supplemented by additional contact after adverse events. Through this, parents felt able to manage problems at home more often, avoiding panic and feeling themselves to be in control. These effects applied to older children (teenagers), too, such that they were able and willing to retain control of their own health, managing both foreseeable and unexpected problems posed by their condition. The families felt no need to go to an emergency department since they had been prepared to deal with most eventualities, and they expressed feelings of self-agency rather than being victims of the illness. Without the service, they felt sure that they would attend the A&E department frequently.

The proactive approach adopted by the specialist nurses was valued. Forthcoming challenges were predicted in good time, and education, training and advice were provided to ensure that a plan was a in place and the skills were acquired to address the situation. This could be changing schools, for example, or a school trip, or even a family holiday abroad. Liaison with school and other health professionals was a welcome part of what the nurses did. The parents spoke of timely intervention as the condition changed, perhaps in response to maturation in the child. The persisting relationship with the specialist nurse, the nurse’s knowledge of the individual child, and the trust that came with that, were vital to the effect of the service.

As a parent of a child with a (lifelong) long-term condition, thoughts about the future were often in the mind. Part of the function of the specialist nurses was to engender a positive outlook on a future that could be normal in many ways, in which the child would thrive and achieve, gradually assuming responsibility for self-care, and accepting the condition as part of life but not a restriction. This attitudinal adjustment brought relief from stress and a more balanced perspective so that the family was no longer always on edge waiting for the next crisis, but rather expecting to deal effectively with issues as they arose and without undue interruption of normal daily life. Attendance at the A&E department was no longer viewed as a routine part of life but an unusual event as for any other parent.

The accessibility of the practitioner was important. Many means of communication were employed. Parents spoke of email, text message and telephone calls as ways of securing advice and reassurance. They regretted that the specialist nurses were not officially available out of normal office hours, though they admitted making contact at any time of the day or week, usually receiving a response. Despite having access to CCNT during the evening and at the weekends, the parents wanted more nurses in post and for this to be 24-hour provision. As part of the integration of the CAON service, the CCNT is the normal out of working hours support on a 7-days per week basis. The notion of a 24-hours service is considered further on page 22.

Summary

Most of those children with long-term conditions who reported a history of admission to hospital required secondary (or tertiary) support in accordance with established protocols, though even these families felt more able to avoid this need in future because of the support from the specialist nurses.

The major impact of the specialist nurses in averting future attendance at urgent care facilities lay in building a skill set and specific knowledge in families so that they were better equipped to cope at home. Foresight and preparation for points of challenge to the family's stability (such as changing school, or trips away) helped to prevent otherwise inevitable disruption to clinical stability and likely need for secondary intervention. However, further impact was exerted in the support of other professionals to recognise the possibility of immediate intervention and return to primary care services without admission to hospital.

Confidence-building was a vital factor in enhancing parental acceptance of their ability to manage more difficult or complex situations with their child's long-term condition. This was said to be a long-term project, too. However, the strongest contextual factor in keeping children away from hospital was associated with efforts to adjust parental attitudes about the child's condition and its effect on their life. Being brought to see a positive future, feeling in control, and recognising powerful self-agency were the most effective deciders of increased self-care and decisions to engage in self-management of clinical challenges. Part of this relied upon perceived intimacy of the family with "their" specialist nurse.

5 CHILDREN'S COMMUNITY NURSING TEAM

The CAON children's community nursing team is made up of a manager and approximately 10 WTE core nurses, offering a service every day of the week (including bank holidays) from 8am to 8pm. The full range of children's community nursing care service is provided with much integrated working with other parts of the wider CAON team. Same-day appointments are available, with referrals from GPs and other health professionals. Longer appointments of one hour are made when needed, for example for an initial consultation for children newly diagnosed with asthma. Whilst a separate service to PNP, the team offers support to patients reviewed and treated at the PNP clinic, particularly through evening checks and follow-up visits.

Children who have been referred to the CCNT who require more specialist review can be handed over internally, with CCNT nurses able to book appointments directly into the PNP clinic diary, giving parents a specific appointment slot on the chosen day. Wrap-around care is provided, then, with PNP clinic nurses, CCNT nurses, and specialist nurses able to draw in additional support for children through internal communication without families feeling that they have been handed off. Flexibility is demonstrated in arranging CCNT appoints to coincide in time and location with other appointments such as undertaking dressings at the same appointment for a health and language assessment, reducing the disruption for families and reinforcing the unity of services.

Detailed care pathways have been produced for a number of illnesses (such as asthma, bronchiolitis, and gastroenteritis) which are shared with GPs to enable understanding of when referral to the CCNT can be made usefully and when secondary service intervention is essential. This is part of the enhanced communication channels that are needed for GPs to be confident of the appropriateness of referral and to persuade parents of unity of this combined primary care effort.

Child A was referred to the team with a diagnosis of extensive encephalomalacia. This condition has resulted in complex health care needs. She has a named nurse in the team acting as key worker, co-ordinating her care and providing the family with regular support visits. The nurse ensures an integrated seamless service with individualised care plans and a hand-held passport, while the epilepsy specialist nurse provides the family with education and support. The family receives support from the complex care coordinator and palliative care specialist nurse. The named nurse implemented a care package for the family and trained care staff to meet A's needs.

The family has been supported to formulate an advance care plan which reflects the severity of the condition. The family's wishes for the little girl's end of life care will inform care from the team alongside the complex and palliative specialist nurse. The latter visits the home regularly with the community paediatrician, responding to any symptoms or changes in health needs in a responsive, proactive manor. She also leads on the non-statutory EHCP plan to guide care provision in support of the family's aspirations for the future through a person-centred approach. The CCNT also provides the family with acute care, making several visits to prevent hospital admission for the child through the ability to examine, diagnose and prescribe acute treatment to avoid further deterioration.

Figure 7: An example of CCNT action to prevent hospital admission

There is a wider impact on reducing the burden of unnecessary attendance at secondary and tertiary care facilities. Members of the team provide training for other professionals, especially supporting health visitors and school nurses in their health promotion work in schools. New GPs are offered the opportunity to shadow CCNT (and PNP) staff in clinics: a

much-coveted facility that is valued by paediatricians and senior GPS. Wider connections are made with similar teams from other NHS organisations, ensuring that updating is continuous through information-sharing.

Summary

The impact on deflecting from attendance at urgent care centres is partly on preventing the first incidence, but also on reducing length of stay and subsequent presentations.

Direct care and coordinating the wider team effort are important ways in which the CCNT deflects children with long-term conditions from urgent care facilities. However, further effect is made by providing follow-up to the efforts of PNP or specialist nurses, offering evening contact by telephone or visit to reinforce reassurance and self-confidence.

Contextually, parents value a personal approach and continuity of care, so the ability of the CAON team to arrange further support in a seamless manner and with immediate confirmation of appointments or visits is crucial. The enhanced communication and efforts to build trust with GPs is also vital if reduction of the overload on GPs is to be effected.

6. DISCUSSION

The elements of realist evaluation were reflected in the evaluation questions.

1. **To what extent does the Paediatric Nurse Practitioner (PNP) service deflect attendance at A&E and admission to hospital?**

There was 100% parental satisfaction with the PNP service. If the PNP service was not available, and in the absence of GP appointments (routine or out of hours) more than 75% of parents would have presented the child at an urgent care facility. Parents repeatedly expressed a preference to use the PNP service in future with similar (non-urgent) problems.

Whilst the initial scope of the research was to test the Paediatric Nurse Practitioner Clinic, evaluation has found that there was also 100% parental satisfaction with the specialist nursing services. Parents of children with long-term conditions stated explicitly that they had been empowered to manage problems at home rather than needing to attend at an A&E department. They expected such attendance to be rare and only when forced by treatment protocol. Data from parents accessing the CCNT was not accessed.

2. **What factors do parents hold to be essential to their decision to use the community-based service rather than to attend an urgent care centre or A&E department (on one occasion or in future)?**

The most important factor in achieving this was the availability of same day appointments, regardless of the time of day. Indeed, the ability to wait at home with the child was appreciated. The time taken by nurses in PNP clinic, in specialist services, and in the community team to listen, offer explanation, provide information (in a variety of media), and to personalise the service for the child was also vital in promoting change in parental behaviour regarding choice of service for non-urgent illness. Thorough assessment beyond the immediate physical health issues was valued, as was help to develop knowledge and a wider skill set to enable self-help in future instances of similar problems. Signalling of forthcoming points of stress or additional need, together with timely preparation with information and training, was instrumental in preventing a default reversion to seeking secondary service help when stability of the long-term condition was challenged. Direct internal communication within elements of the CAON service ensured tangible “wrap-around” of support for the family, while flexibility of evening review of improvement, together with readily-accessible targeted media in leaflets and on Facebook provided a more reliable source of ongoing support than general Internet materials.

These issues are supported by the international literature. Early access due to perceived urgency and likely deterioration of the child’s condition was also a factor for Irish (Breen & McCann 2013), Canadian (Smith et al 2015), Lithuanian (Burokiene et al 2017), Belgian (Benahmed et al 2012), American (Grigg et al 2013, May et al 2017), Singaporean (Kua et al 2016) and other British (Holden et al 2017, Ogilvie et al 2016) parents. Low health-literacy was a compounding reason for misinterpretation of the degree of severity of the child’s presenting signs and symptoms (Burokiene et al 2017, May et al 2017). Fever was a predominant concern (Grigg et al 2013, Maguire et al 2011, May 2017). A recent literature review in Northern Ireland shows that the picture of causality of unnecessary attendance at urgent care facilities is complex and multi-factorial (Butun et al 2019). The role of education in altering parental choices has been shown to be effective in the US, Norway, and the UK (Davis et al 2018, Ruud et al 2017, Watson & Blair 2018).

3. What contextual factors are at play in influencing this decision?

A polite, professional approach was said to be important – often in contrast to the rushed consultation in other time-pressured services. This linked to the professional being friendly and accessible, as well as showing skill in interaction with the child. Even with a busy clinic or visit list, the nurses maintained a stress-free atmosphere, offering reassurance, and avoiding any suggestion of blame, time-wasting or inappropriateness of the reason for seeking help. This latter was based on a pervading notion that if a parent is sufficiently concerned to seek help about a child then they are demonstrating positive parenting behaviour. The professional response should be to inform, explain and empower to avoid future need. With parents of children with long-term conditions, particularly, this involved extensive work of confidence-building. Effectively, adjustment of the family attitude to one of recognising a positive future and discovering enhanced self-agency was the essential context in which change in help-seeking behaviour occurred.

Lack of trust in general primary care practitioners' competence with children, and a desire for high-quality, specific paediatric expertise features in many parents' decision-making (Kua et al 2016, Ogilvie et al 2016, Smith et al 2015). Expectations of better equipment for diagnostic purposes went along with this. British and US parents, particularly, sought reassurance and confirmation of their own self-care ability (Ogilvie et al 2016, May et al 2017), and when information was lacking, it has direct consequences on future need to attend secondary or tertiary centres (Holden et al 2017). The CAON service makes considerable efforts to work in tandem with other primary care practitioners, notable GPs, health visitors and school nurses, ensuring effective communication, and clarifying the *complementary* nature of the offer that is made. GPs appear to understand what the CAON service can do, particularly in alleviating the overall burden of demand for review of children with non-urgent illness from parents who, understandably, seek a same-day consultation, and who will benefit in terms of health promotion and up-skilling for future occasions from a longer consultation than is normally possible. An initiative in Tameside to provide GPs and practice nurses with rapid access to a paediatrician for advice on more urgent cases which lie on the borderline of need for secondary service review has also proved to be particularly successful.[1]

4. What opportunities are there for wider learning for the partnership, Greater Manchester, and beyond?

The initiative has demonstrated that alternatives to attendance at an emergency department or urgent care centre can not only be acceptable to parents but may become a preference if the required factors are in place and contextual factors are addressed. While context differs geographically, the factors that are central to behavioural change in seeking support with non-urgent illness remain unchanged. There is evidence that parents wish to continue with services that they know and with which they have been satisfied previously (Smith et al 2015). Developing awareness of an alternative service to urgent care and ensuring a positive experience on first use are vital if selection behaviour is to be changed.

An integrated system, with elements able to book directly into other elements to ensure escalation or continuity of care such that parents experience a seamless service acts to

[1] https://www.rcpch.ac.uk/resources/knowledge-exchange-sessions-gps-tameside-hospital

reinforce parental confidence and self-agency. Rapid access, information-provision in multiple formats, and building of parental skill to identify and manage non-urgent problems, are important to parents. Convenience with shorter waiting time is a recurrent factor in parental decision-making (Benahmed et al 2012, Breen & McCann 2013, Grigg et al 2013, Smith et al 2015).

Extra time is needed in appointments to achieve these outcomes (the main reason for dissatisfaction with GP options after absence of appointments). The time can be used in proactive health promotion and knowledge-enhancement for families which, in turn, increases the likelihood of opting for self-management.

After-hours (weekend and evening) access to a service is a common call internationally (Burokiene et al 2017, Kua et al 2016, Smith et al 2015). However, calls for a 24-hour, 7 days service and more nurses require more interpretation. Certainly, a 7-days service is both desired and provided at least in parts of the system. On deeper investigation, a long-day service (perhaps 8am-8pm) was what parents valued. An informal rule of thumb that if parents are sufficiently concerned to take a child out of bed to the emergency department, then they are likely to be retained at least for observation seems to hold true, so providing a service from early morning until after bedtime (for the age group accessing services in this evaluation) was more accurately what parents sought, rather than a 24-hour provision. This still leaves a weakness in specialist nurse provision, which cannot be made available on this scale with only a single epilepsy nurse specialist and a single diabetes nurse specialist, despite the cover offered by the CCNT.

Advertisement of the service to the public and to professionals is essential. Once parents were aware of the nurse-led clinics, for example, they wished to prioritise that service in future. Holden et al (2017) recognised that parents were influenced by “stable brands” so implanting a positive image of (for example) PNP clinics as a high quality and stable brand is important for achieving deflection to such a service from urgent care centres. GPs, other professionals, and at least one urgent care centre are keen to refer families to the service, too. This depends upon the professionals knowing of the service and understanding what can be offered. CAON spends considerable time in liaison with schools and activity groups such as Brownies, in updating GPs, health visitors and school nurses, and in public broadcast on radio stations. Globally, it seems, parents attend urgent care facilities with non-urgent problems on the advice of health and other professionals, including GPs (Burokiene et al 2017, Ogilvie et al 2016, Smith et al 2015). Addressing this behaviour in referring practitioners must also be part of the solution.

8. REFERENCES

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Appendix 1: The local Friends and Family Test questionnaire

Children's Nurse Practitioner Service

NHS
Pennine Care
NHS Foundation Trust

We would like you to think about your recent experience regarding the Children's Nurse Practitioner Service and would appreciate your feedback.

1. How likely are you to recommend our service to friends and family if they needed similar care or treatment?

2. Please can you tell us the main reason for the answer you have chosen to question 1?

3. How happy were you with the service provided today?

4. If this service was not available, where would you have taken your child?

Out of hours doctor (BARDOC) ☐

Urgent Care Centre (Rochdale Infirmary) ☐

A&E department:
Bury ☐ Oldham ☐ North Manchester ☐

Managed your child at home ☐

Other (please specify).....

5. Is there anything else you would like to tell us about the service provided to you and your child today?

Thank you for taking the time to provide your feedback, your comments are very much appreciated.

Date of publication: May 2018 Reference: 5895

Appendix 2: The forced ranking scale for parents

Evaluation of the PNP service

[1=least important 2=fairly important 3=most important]

Thinking first, then, about Access to the service...

(a) Ease of access (contacting and getting to the service)	1	2	3
(b) Availability of same day access	1	2	3
(c) Length of wait & being seen on time	1	2	3

Which do you think is MOST important?

Of the other 2, which is LEAST important?

Please think about aspects of Clinical Care…

(a) Attention and interaction with the child	1	2	3
(b) Knowledgeable, giving explanation and information	1	2	3
(c) Reassuring, giving support, and understanding	1	2	3

Which do you think is MOST important?

Of the other 2, which is LEAST important?

Tell me how you rate these aspects of Staff Attitude…

(a) Being good with the children	1	2	3
(b) Being friendly	1	2	3
(c) Being polite and professional	1	2	3

Which do you think is MOST important?

Of the other 2, which is LEAST important?

Appendix 3: Research Ethics Committee approval letter

University of Salford MANCHESTER

Research, Enterprise and Engagement
Ethical Approval Panel

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4 February 2019

Dear Tony,

RE: ETHICS APPLICATION–HSR1819-033 – 'Evaluation of Rochdale Family Services Model pilot project to reduce admission to hospital of children with long-term health conditions.'

Based on the information that you have provided, I am pleased to inform you that ethics application HSR1819-033 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Professor Sue McAndrew
Chair of the Research Ethics Panel

NHS
Heywood, Middleton and Rochdale
Clinical Commissioning Group

University of Salford MANCHESTER

NHS
Bury & Rochdale
Care Organisation
Northern Care Alliance NHS Group

Long T, Mitchell C (2019) Realist evaluation of the impact of paediatric nurse practitioner clinics, specialist paediatric nurses, and a children's community nursing team in deflecting attendance at emergency departments and urgent care centres by children with long-term conditions. University of Salford with NHS Heywood Middleton & Rochdale CCG. ISBN: 9781912337361

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GMCA GREATER MANCHESTER COMBINED AUTHORITY

NHS
in Greater Manchester